

GUIDELINES FOR USING CALIFORNIA BIRTH DEFECTS REGISTRY DATA

Case Definition

Although the registry monitors over 200 conditions, many are quite rare. This report highlights five specific types of birth defects present in births occurring during the calendar years 1997 through 2006. They are common, serious, and have substantial public health impact.

Cases included in this report met the following criteria:

- The baby was live born, stillborn \geq 20 weeks of gestational age, or medically terminated.
- The baby met the diagnostic criteria for the following birth defects: select heart defects, neural tube defects, oral cleft defects, abdominal wall defects and trisomy 13, trisomy 18, and Down syndrome (trisomy 21). Appendix B (see page 117) lists the BPA codes used to define these defects.
- The diagnosis was made before the baby reached one year of age.

Multiple Birth Defects in the Same Baby

A baby can have more than one birth defect and can be counted as a separate case for each defect (i.e. child with cleft lip and spina bifida will be counted as a case of cleft lip, and again as a case of spina bifida). Therefore, the defect data do not necessarily represent mutually exclusive cases. It is important to recognize that adding up the number of defects will not yield the number of babies with defects.

Demographic characteristics

CBDMP registry cases are linked to live birth and fetal death certificates from California's Vital Statistics Division, the source of the demographics reported.

Mother Age at Delivery:

The mother's age classifications used in this report are:

- 13-24 years
- 25-34 years
- 35-55 years

Mother Race/Ethnicity:

The mother's race/ethnicity classifications used in this report matches other state Maternal, Child and Adolescent Health reporting standards:

- White: White/non-Hispanic
- Hispanic: Any race/Hispanic; includes Mexican, Mexican-American, Chicana, Puerto Rican, Cuban, Spanish, other Hispanic origin
- Black: African-American/non-Hispanic
- Asian/Pacific Islander: Asian/non-Hispanic, Pacific Islander/non-Hispanic, Japanese, Korean, Vietnamese, Asian Indian, Cambodian, Laotian, Hmong, Thai, Filipino, Hawaiian, Guamanian, Samoan, other Pacific Islanders
- American Indian: American Indian, Aleut, Eskimo

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Mother Education:

The vital statistics program coding for mother education has changed over the 10 years included in this report. The description of the categories included in the mother's education tables is:

- 8th grade or less: includes no formal education
- High school: includes some high school and high school graduate
- College: includes post graduate high school and some years of college

Data Analysis

Small numbers:

Small numbers of cases can create analysis problems, such as unstable rate estimates. In case of a rare defect or areas with a small population, the issue of small numbers can arise. The addition of a single birth defect will make the rate for a particular year appear much higher than usual. The fluctuation over time may not be statistically significant. Since a small change in the number of cases reported can result in a relatively large change in rates, caution should also be used in comparing annual rates for a specific defect.

Birth Defect Prevalence Rate:

When examining data, a birth prevalence rate better reflects occurrences in a population than does the number of cases. Birth prevalence was calculated as follows:

$$= \frac{\text{number of birth defect cases}}{\text{total number of live births* and fetal deaths*}} \times 10,000$$

For 10-year graphs in the Central Valley region, three-year moving rates (centered around the middle-year) were calculated to “smooth” the data so that trends are more discernable. It also helps filter out outliers for any particular year due to random fluctuation. Prevalence rates were calculated for all regions and for each specific demographic group: mother age, and mother race/ethnicity, and mother education.

*Includes all pregnancy outcomes: live births, stillborn >= 20 weeks gestational age, and medically indicated terminations

Confidence Intervals:

The birth prevalence rate for a specific defect is the best estimate of the true prevalence. To understand the range of possible values for the true prevalence, we calculate the 95% confidence interval for the 10-year time period. From a practical viewpoint, confidence intervals are particularly useful when dealing with small numbers of cases or where the birth defect prevalence for one group will be compared with that of other groups. It helps minimize reader concern about

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prevalence values that appear high or different when in fact it is most likely due to random fluctuation.

For small numbers of cases (less than 100 cases), Poisson distribution was used.¹ For a large number of cases, the normal distribution was used.² It is important to understand that others in the field may not use the same methodology.

References:

1. National Birth Defects Prevention Network (NBDPN). *Guidelines for Conducting Birth Defects Surveillance*. Sever, LE, ed. Atlanta, GA: National Birth Defects Prevention Network, Inc., June 2004.
2. Rothman KJ, Boice JD Jr. *Epidemiologic Analysis with a Programmable Calculator*. Boston, MA: Epidemiology Resources Inc.; 1982.

Limitation of the Data

Lack of Statewide Data:

In the early 90's, CBDMP monitored all 58 California counties. However, due to significant budget constraints, monitoring for birth years 1997-2006 has been scaled back to include a subset of the population (about 41% of annual births in California). Currently, data collection occurs in the Central Valley Counties, San Diego County, and Orange County. Monitoring was conducted in Riverside and San Bernardino Counties, but has recently been discontinued.

Although this subset represents the state's geographic, environmental, and racial/ethnic diversity, we are unable to provide statewide data for birth defects. However, the "Expected Ranges of Annual Cases Prevalence by County" table (see page 55) provides estimated ranges for all counties. This is based on the average annual number of births & adjusted mother's age using 2004-2006 data for the Central Valley region.